SCLERODERMA ASSOCIATION OF B.C.

The Bulletin

FALL-WINTER 2024-2025 | VOLUME 6 NUMBER 2

Scleroderma Association B.C.

Energy management

Systemic Scleroderma and Cancer

Summary

Contact :
Scleroderma Association of B.C.
PO Box 16155 Lynn Valley
North Vancouver BC V7J 3H2
Phone: 604-371-1005
Email: info@sclerodermabc.ca
www.sclerodermabc.ca

The Bulletin
Michele Gervais

Graphic Designer
Antonella Battisti - GrafistaDesign

If you no longer wish to receive this printed magazine or would like instead to receive it electronically, please let SABC know at info@sclerodermabc.ca

ISSN 2562-5780

Board of Directors

Rosanne Queen
President
604-984-9425
sabc.rq@telus.net

Michele Gervais
Vice President
604-761-7782
gordmich17@gmail.com

David Queen
Secretary
604-619-5820
dq.sabc@telus.net

Patrick Livolsi
Treasurer
778-791-7834
treasurer@sclerodermabc.ca

Emilio Chiarizia
Board Member
604-250-5250
emilio.mdp@telus.net

Chelsea Fitzpatrick-Lindsay
Board Member
778-288-0936
chelsea@sclerodermabc.ca

Kelly Grant
Board Member
604-378-1806
sabckelly@gmail.com

Amir Pourghadiri
Board Member
604-349-4986
amirpourghadiri@gmail.com

Amyn Rajan
Board Member
604-418-7237
amyn@sclerodermabc.ca

Kenny Reid
Board Member
604-760-8024
kr67.sabc@gmail.com

Cecille Soriano
Board Member
778-887-6405
sabc.cecilles@gmail.com

Emilie Wang
Board Member
778-700-6518
emwang29@student.ubc.ca

A Word from Our President

As we celebrate SABC's 40th anniversary, it is truly remarkable that for all these years an all-volunteer registered charity has raised over $1 million for research while staying true to its mission statement. This achievement is a testament to the incredible people who have passionately stepped up to help others.

And our success is not solely due to the dedication of our board members; it's the collective effort of every community representative, every person who has donated, fundraised, or shared their story. Each time someone explains what scleroderma is—to a family member, friend, medical professional, or even a grocery store clerk—it keeps us connected to the vision that Joan Kelly and those remarkable women set in motion so many years ago. We are all part of this journey together, honoring their legacy and continuing their work with every conversation and every act of kindness.

There are two new articles from Sclérodermie Québec in this edition. Many of us can relate to their messages within. I encourage everyone to stay up-to-date on all necessary health screenings, especially cancer screenings, and to discuss the recommended timelines with your doctors. Speaking from personal experience, I am grateful I did not wait the typical two years for my mammogram, allowing me to catch my breast cancer early.

This year's AGM and Conference was a resounding success, and it was a joy for me personally to reconnect with old friends and welcome new ones. I reviewed the feedback from the completed surveys, and as expected, our new members found our community to be knowledgeable, supportive, and positive. For those needing extra support, I encourage you also to join us on our Zoom meetings and webinars.

I look forward to another year as President, working alongside such a wonderful community.

ROSANNE QUEEN
President
Scleroderma Association
of B.C.

*As we approach the Christmas season,
I wish you and your loved ones
a joyful and safe celebration.*

Moving to Cure SCLERODERMA

WALK - RIDE - GROOVE

2 EVENTS - JUNE 2024

June 1st, across Canada, starts Scleroderma Awareness Month which involves raising awareness and much needed funds for research. The yearly campaign ends on June 29th, World Scleroderma Day.

JUNE 16 SCLERODERMA RIDE FOR RESEARCH

Our 13th Annual Scleroderma Ride for Research was a resounding success! Over 75 participants gathered with us—not only to cycle, to walk or to enjoy our potluck lunch, but to come together in a powerful show of support, raising critical awareness and essential funds for life-changing scleroderma research. With the dedication of eight amazing fundraisers, **we raised an incredible $56,884.44**, adding to our ongoing ***"Moving to Cure Scleroderma"*** campaign.

After 13 years of organizing this event, I am endlessly inspired and deeply humbled by the steadfast support from family, friends, colleagues who show up year after year and from the new members of our scleroderma community. It's heartening to know that with so many worthy causes to support, our donors choose us because SABC commits 100% of every dollar raised directly to research. This support fuels our hope, our drive, and our belief that, together, we're making a real difference.

ROSANNE & DAVID QUEEN

JUNE 8, GROOVE FOR A CURE

If you think a charity event can't be both fun and life-changing, you clearly haven't been to Kenny's ***"Groove for a Cure"*** night! We rocked out with 80's cover band legends 17West, and let me tell you, we weren't just dancing—we were dancing for a cause. The energy in the room was electric (in true 80s rock fashion), with over 220 people singing, dancing, and auctioning off everything from hairdryers, hotel rooms, restaurant vouchers and so much more. **But it wasn't just about having a good time—it was about raising awareness and over $14,000 to help fund vital research for Scleroderma and SABC.**

And let's talk about the real MVPs here: everyone who came, donated, bid on items, and spread the word. You turned up in droves, and together, we made it clear that when we groove for a cure, we do it big. (Next year's gig? It's going to be even bigger. And probably louder. Get your earplugs ready.)

A huge thank you to all the friends, family, and rock stars (yes, that's all of you)—both on and off the stage—who made this night a success. We're already counting down the days until next year's event. Let's keep the groove going! Rock On.

KENNY REID & 17WEST

ALL OF JUNE, MOVING TO CURE SCLERODERMA

The **Anywhere in B.C. virtually Moving to Cure Scleroderma 2024 had another successful year raising over $14,500**. A big heartful shout out to all the amazing Scleroderma Warriors, family and friends who get out every year, spread awareness and raise funds for research to find a cure for Scleroderma. Thank you to: **Jennifer Beckett** *(Jen's 2nd Conquer the Lake Scleroderma Run)*, **Chris Dolbec, Jackie Alexander, Kelly Grant, Linda Barnes, Kiah Grafton, Taran and Teressa Colosimo** *(Yoga with Teressa)*.

TERESSA COLOSIMO

This years **Walk/Move for Scleroderma** was a huge success. I am grateful to my wonderful family and friends that continuously show their support by spreading awareness and making donations that help fund important research that will hopefully one day lead to a cure. I couldn't do it without you, thank you!

JACKIE ALEXANDER

LIGHTING UP THE WHITE ROCK PIER

On June 29th, World Scleroderma Day, a group of us gathered at the iconic **White Rock Pier,** illuminated in scleroderma blue, to celebrate the success of the ***"Moving to Cure Scleroderma"*** campaign. The evening was filled with gratitude and camaraderie, capped off by dinner and an unforgettable ice cream run—my first time braving the cold and drizzle for a sweet treat! Special thanks to Sandra-Marlene Hapke for her dedication in securing the City of White Rock's acknowledgment of this important day. Celebrated across the globe, World Scleroderma Day reminds us that we are united in raising awareness, building community, and advancing toward a cure.

ROSANNE QUEEN

A big Thank-You to the event organizers of the *new to this year*, Groove for Scleroderma music concert in Ladner/Delta, the Scleroderma Ride/Walk for Research in Vancouver and the Virtual Moving to Cure Scleroderma - Anywhere in B.C. You all made this June's events truly special and we owe our success to all your hard work!

And especially, our heartfelt thanks to our caring donors who supported June 2024's campaign. B.C. scleroderma patients, their families and friends again did their part by raising over $100,000 for research.

Thank you to Global BC for promoting our June Awareness Campaign

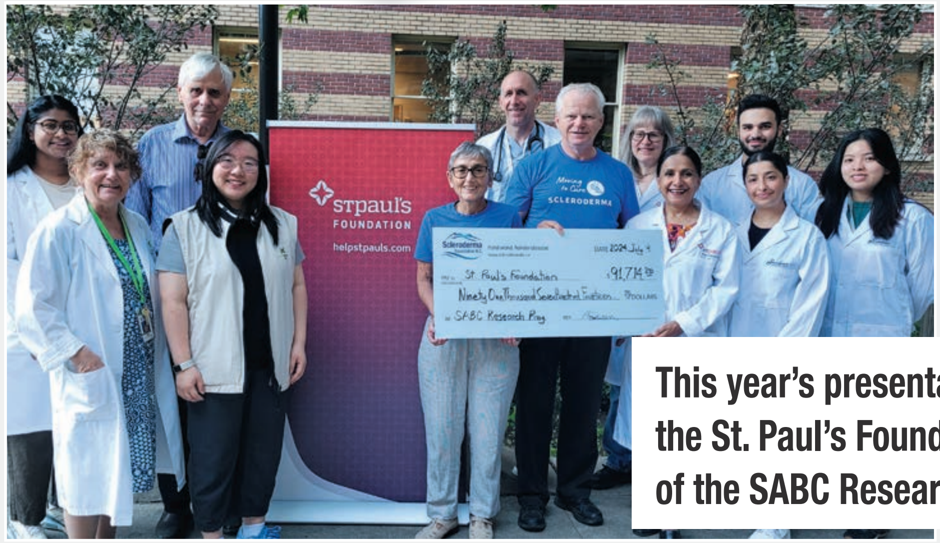
Global BC

Thank You!

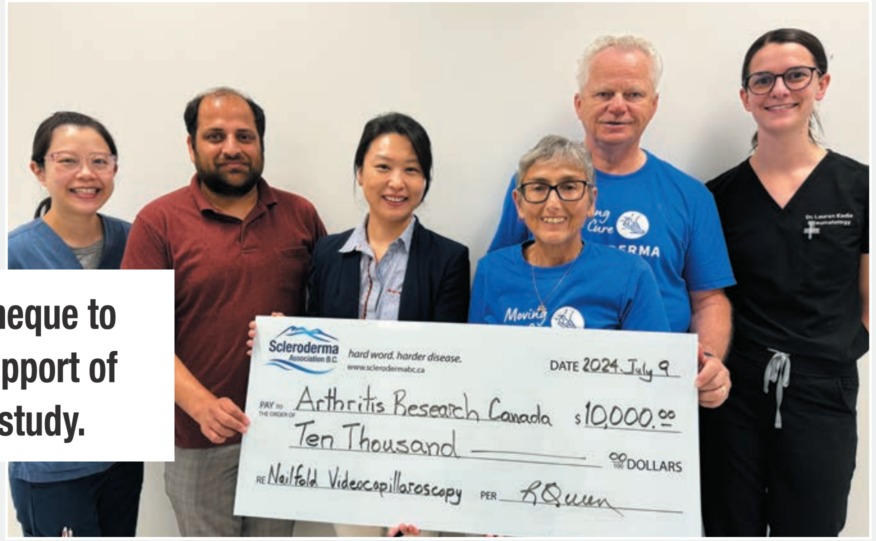
We raised

$101,714.25 in 2024

ALL MONIES RAISED DIRECTLY SUPPORTS SCLERODERMA RESEARCH IN B.C. AND CANADA



This year's presentation of a $91,714.25 cheque to the St. Paul's Foundation for the continued support of the SABC Research Program.



And the presentation of a $10,000 cheque to Arthritis Research Canada for the support of Dr. Hyein Kim's Videocapillaroscopy study.

AGM and Conference Highlights

Eighty-six patients, their supporters and SABC associates attended this Fall's 40th Annual General Meeting & Conference in Burnaby on Saturday, October 26th.

AGM HIGHLIGHTS

- **Reviewed a recap of last fiscal year's activities and financials (May 2023 to September 2024)**
- **Sincerely thanked our two retiring SABC Board Members and welcomed the new 2024-2025 Members**

Cecille Soriano is a 2019 lung transplant recipient and scleroderma warrior.

Emilio Chiarizia is a small business owner, decision maker and wearer of many different hats in his day-to-day business affairs and many volunteer roles.

Emilie Wang is a second-year medical student at UBC.

Presented the **Lihong Yang Memorial Scholarship Award** to UBC medical students **Amir Pourghadiri** and Helen Hsiao *(in absentia)*.

Video recordings of the conference presentations will be available at **www.sclerodermabc.ca**

AGM and Conference Highlights

SPEAKER HIGHLIGHTS

UPHEAVAL, CONNECTION & MEANING-MAKING: REFLECTIONS ON COPING WITH SCLERODERMA

DR. JOE PELLIZZARI

The demands for coping with scleroderma are tremendous! In his presentation, **Dr. Pellizzari** discussed three categories of coping with the anxiety: problem-focused (learn a lot about the disease; become an SABC volunteer); emotion-focused (be social; have a hobby; try relaxation techniques/mediation/prayer); meaning-making focused (accept and prioritize what is important; take one day at a time). Dr. Pellizzari ended his presentation discussing the importance of connection. Building a strong support network and maintaining connections with loved ones is an important strategy for coping with chronic illnesses such as scleroderma. For support with coping with scleroderma please reach out to SABC or SPIN (Scleroderma Patient-centered Intervention Network). SPIN is working on programs to help people with scleroderma cope with their illness and manage their daily lives.

Take away tips: By making connections we can help ourselves and one another cope with scleroderma.

SCLERODERMA AND THE GUT

DR. SARVEE MOOSAVI

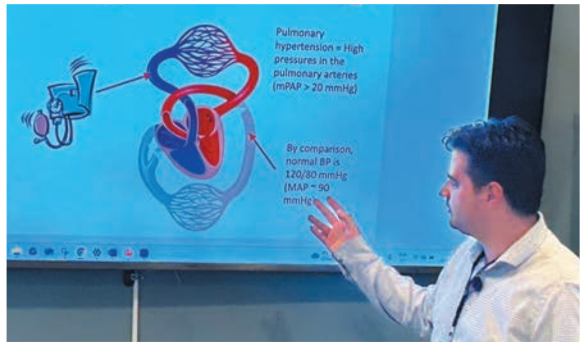
Dr. Moosavi presented a comprehensive overview of gastrointestinal (GI) manifestations in people with scleroderma, noting that 80-98% of individuals with the condition experience GI symptoms. She explained the role of gastrointestinal motility—the coordinated movement of food and digestive content through the GI tract—and how scleroderma affects it. In the disease, inflammation, collagen deposits in the muscle layers, and nerve damage disrupt motility. Dr. Moosavi discussed both upper and lower GI tract symptoms in scleroderma patients. For each symptom, she highlighted relevant diagnostic tests available in BC, lifestyle modifications that can help improve gut health, and pharmacological treatment options.

Take away tips: Diagnosing and treating a multi-system disease like scleroderma requires a multi-disciplinary approach. Because GI complications are mainly driven by abnormal motility, treatments should be tailored to the predominant symptoms in each patient.

AGM and Conference Highlights

PULMONARY HYPERTENSION IN SCLERODERMA

DR. NATHAN BRUNNER



Dr. Brunner started out his presentation explaining to us the difference between pulmonary hypertension (PH) where high blood pressures exist within the pulmonary arteries of the heart and the rarer, smaller subset of PH, pulmonary arterial hypertension (PAH) which is associated with other medical conditions like systemic sclerosis where pressures are elevated due to thickening, narrowing and fibrosis of the small pulmonary arteries. He then described the symptoms of PH and how they test for it using blood analysis, ECGs, x-rays, pulmonary tests, echocardiograms and for PAH, cardiac catheterization. Lastly Dr. Brunner discussed the immense variety of pharmaceutical drugs used to treat PH; on their own or in combination.

Take away tips: You know the medications prescribed and taken are working when you overall are feeling better, you can walk farther and your blood results and echo results are better. If you aren't noticing these improvements, the plan is to conduct another heart cath and add more or different medications. Only when you reach the maximal therapy without relief is lung transplantation discussed.

LISA KOLKMAN

Lisa Kolkman's presentation perfectly complemented Dr. Brunner's with an emphasis on providing strategies to preserve the lung function you have; to live the best life you can for as long as you can. Her 8 strategies: Early detection, Medication adherence, Immunizations/Iron deficiency, Supplements/stimulants, Prevention of heart failure, Exercise, Mental Health and Health literacy/Self advocacy were discussed in detail.

Take away tips: As with any strategy to better your health and outlook, consistency is key. You know yourself best but it is impossible to know everything about your condition and it's never too late to learn. Learn to choose the right person for the problem at hand and learn to communicate clearly and concisely your health challenges on a priority basis.

40th ANNIVERSARY CELEBRATION HIGHLIGHTS

We raised a glass of sparkling juice to toast SABC's 40th anniversary, celebrating its history and founders. Bob Buzza, the brother of founder Joan Kelly, an incredible Scleroderma Warrior, spoke of the SABC's journey to where we are today. We enjoyed mingling with old friends and meeting new members, welcoming them to the scleroderma community.

Testimony

Rosanne's story

LIVING WITH A DISEASE THAT HAS NO CURE!

When you're told upon diagnosis you might only have five years left because of a disease with a name you can barely pronounce, it changes you in ways you could never expect.

Every day, I'm reminded of the conditions I carry with me: Raynaud's, Scleroderma, Rheumatoid Arthritis, Sjögren's, GERD, Interstitial Lung Disease, and as of March 2025, I will be a two-year breast cancer survivor. Living with these challenges has shown me just how fragile life really is.

The journey hasn't been easy. In 1992, when my doctor first diagnosed me with Raynaud's Syndrome, I had no idea what it meant. Raynaud's causes my blood vessels to constrict, especially in my hands and feet, turning them white, purple, blue, and finally pink again. Keeping my body warm is constantly an issue even during the summer with those lovely summer breezes and air conditioning.

In 1997, I was diagnosed with scleroderma, and my world turned upside down. My then, rheumatologist explained that "scleroderma causes hardening of the skin and organs", and he warned me I might have a few years left. He advised me "to return if my symptoms worsened so he could help keep me as comfortable as possible". I was stunned, at that time, my only symptom was a slightly thickened skin patch on my thumb!!

After sharing a good cry with my husband David, I resolved not to give up hope. Instead, I chose to live fully and find joy wherever I could. I'm not one to sit back and let life happen to me. After the diagnosis, David and I decided not to wait to live our lives. We crafted a bucket list and set our sights on tandem cycling and travelling. Though I've lost strength and dexterity in my hands and wrists, my legs remain strong, and my spirit is determined.

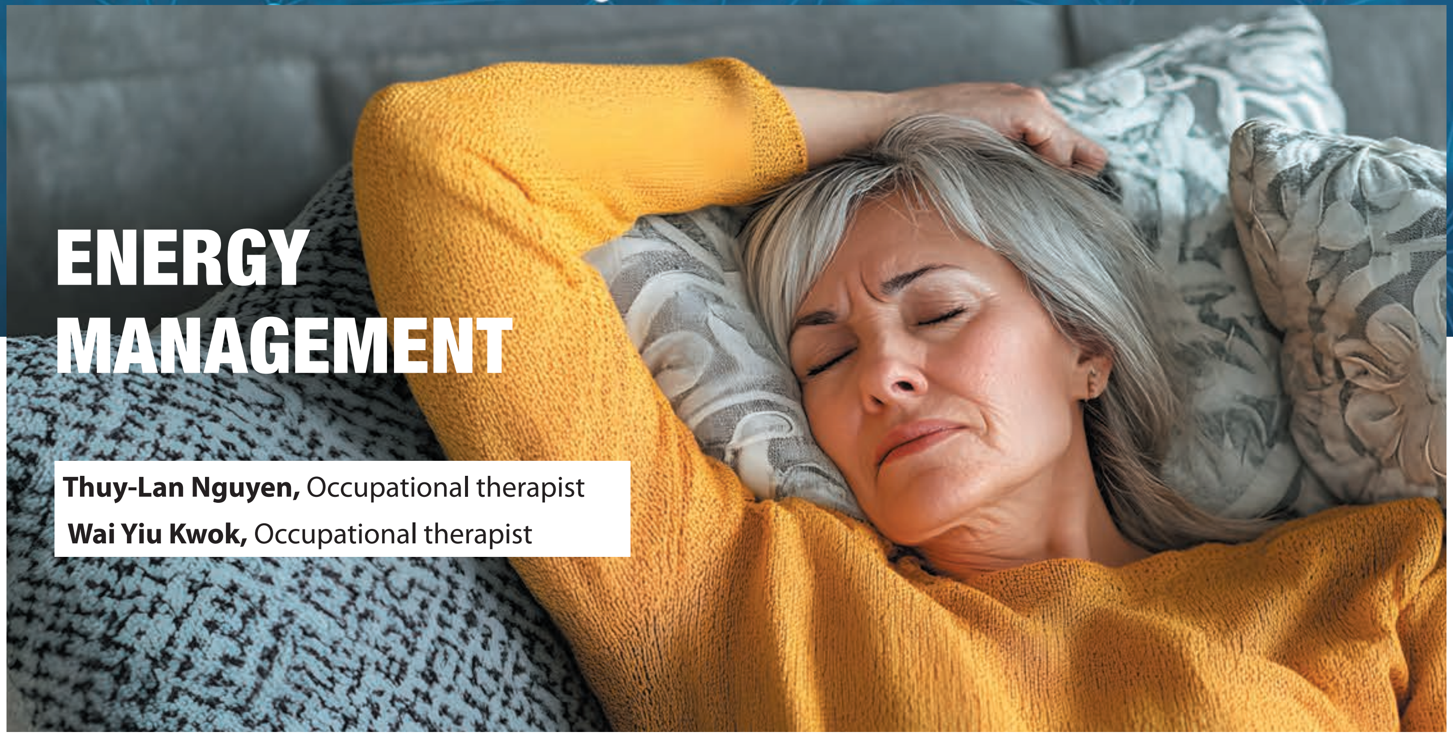
Our trips have taken us through the diverse landscapes and cultures of Australia, Ireland, France, Denmark, Germany, Austria, and even close to home. Without the bike, we have travelled to Italy, the UK and Africa. This journey has been about more than just seeing the world—it's about experiencing the fullness of life together, against all odds. Staying active has been essential for my health, and with an electric motor now added to our tandem, I'm grateful I can still experience this joy while keeping my body strong.

Every day, I'm thankful for the love and support of my husband, David, as well as our family, friends, and my incredible medical team—rheumatologist, gastroenterologist, family doctor, chiropractor, massage therapist, physiotherapist, and podiatrist.

Over the years, scleroderma has definitely left its mark on my body—on the outside: swollen hands and curled fingers, calcinosis, ulcers, a tightened face and on the inside: acid reflux that makes swallowing difficult. Do I worry about continuing to see my fingers become shorter due to a lack of blood flow? Of course I do, but I've also learned that worrying doesn't change a thing.

In the meantime, I continue to laugh, love, and savor good food—sometimes in small bites, but always with deep appreciation. Each challenge has taught me resilience and the power of finding the silver lining. With the right balance of medication, exercise, and a positive outlook, I manage the daily pain and discomfort while maintaining a fulfilling quality of life. So, when people ask how I'm doing, my answer is always, "Could be worse, so life is good!"

After 27 years with this disease, here's what I've learned: Don't rely on Dr. Google. Make sure you're getting information from trusted sources. SABC provides excellent, up-to-date resources. Connect with the scleroderma community; they are knowledgeable, supportive, and incredibly positive. And most importantly, remember that each of us is unique. Don't assume you'll experience every symptom, there will be good days and not so good days. Don't focus on statistics like the five-year mark - I'm living proof that anything is possible!!



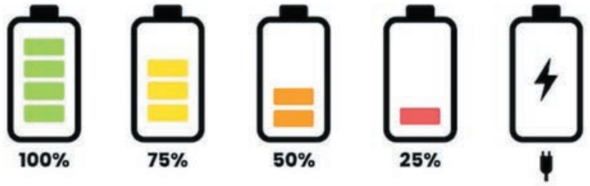
ENERGY MANAGEMENT

Thuy-Lan Nguyen, Occupational therapist
Wai Yiu Kwok, Occupational therapist

Scleroderma is an autoimmune disease that consumes a portion of your energy. Among other factors, the fatigue you may experience can be linked to the inflammatory process, organ dysfunction, sleep disturbances, side effects of medication, nutritional deficiencies, mental and emotional stress, or reduced physical activity. It is therefore normal for fatigue to be one of the common symptoms of this condition. However, there are strategies to manage your energy levels.

THE BATTERY ANALOGY

First, it is essential to understand energy use, which can be compared to a smartphone battery.



Often, we start the day with our phone charged at 100%. Naturally, the battery drains with use. Some activities, like watching videos, consume more battery. Regardless of the type of activity, the battery inevitably drains and needs recharging.

However, we often wait until the battery is at 5% or even 0% before plugging it in. In this digital age, we may also be impatient for it to fully recharge. This can lead to the need for frequent recharging, operating with a low battery, and a disruption in productivity, particularly when the phone is needed for urgent tasks.

This analogy applies to you. If you only take breaks when you are completely exhausted, it takes time to recover. Additionally, if you don't allow enough time for recharging, you will constantly feel tired, as your energy level will remain low. It is, therefore, important to recharge your battery before it runs empty.

THE BASICS OF ENERGY MANAGEMENT: THE 5 'P'S

For effective energy management, it is beneficial to explore the application of the 5 'P's:

1. Pacing
2. Prioritizing tasks and activities
3. Planning your time
4. Positioning and posture
5. Problem-solving

1. PACING

- Get to know and respect your capacities and limits.
- Break an activity into several steps and include rest periods (relaxation, meaningful activities, etc.) between them.
- Alternate between light and heavy tasks.
- Take breaks in the morning, noon, and evening; or, if possible, about 10 minutes every hour to prevent excessive fatigue (which facilitates recovery).
- In your activities, adopt a calm rhythm, with a steady, moderate pace rather than a fast one.
- Work in a pleasant, temperate, and relaxing environment.

2. PRIORITIZING TASKS AND ACTIVITIES

- Analyze your daily activities and rank them by importance in your schedule.
- Is this task essential?
- Does this task need to be done TODAY?
- Do I need to do this task myself? (ask for help or delegate).
- How can I simplify this activity?
- Evaluate the possibility of eliminating or delegating some tasks to allow you to accomplish more meaningful tasks.

3. PLANNING YOUR TIME

- Organization is key to planning. Creating a typical weekly schedule is a good way to start.
- Have a flexible and realistic schedule with regards to the time allocated for each activity (i.e., considering your capacities and limits).
- Spread your activities and heavy tasks over an entire week.
- Plan your essential activities for when you have the most energy.
- Plan your outings.

  Example: If you go shopping, make a list, prioritized by the places you need to visit and items to buy.

  Example: Prepare everything you need before starting an activity (recipe, study materials, gardening tools, etc.)
- Schedule personal time and leisure activities.
- Use what is available to conserve energy, such as elevators, food processors, frozen vegetables, etc.

ENERGY MANAGEMENT

4. POSITIONING AND POSTURE

- Adopt a good posture to prevent fatigue and physical stress. Frequently change your posture to keep your joints moving.
- Sit down for certain activities, such as meal preparation, ironing, folding laundry, or talking on the phone (saving about 25% of your energy compared to standing).
- Organize your workspace according to ergonomic principles.
- Adjust the height and organization of work surfaces (surface should be level with your elbows).
- Arrange storage areas in a functional way (place items you frequently use between shoulder and hip height).
- Use postural aids and technical aids as needed.
- Use tools to facilitate each task, such as longer handles or larger, cushioned grips.

5. PROBLEM-SOLVING

- Be creative, resilient, and patient in finding solutions.
- Be open to changing your habits and doing things differently.
- Try new activities.
- Consider restructuring your schedule.

OTHER STRATEGIES TO REMEMBER:

Negative attitudes can affect your quality of life. Learn to communicate your needs. Here are some attitudes to adopt:

- ▶ Remind yourself that it's normal not to be able to do everything.
- ▶ Remember that results are not always visible while you are taking action.
- ▶ Focus on the positives.

Allow yourself to say "no" to some requests from others and to some of your own demands. Understand that stress can stem from how you interpret events, situations, etc. Remind yourself that any new situation/condition can lead to somewhat exaggerated reactions. Allow yourself to step back when faced with new challenges.

When you need to communicate your needs effectively to better manage your energy, ask yourself the following questions: ***To whom should I speak? When? Where? How?***

Change certain habits: reduce those that drain you and increase those that give you energy.

For example:

- ▶ Engage in physical exercise appropriate for your condition.
- ▶ Improve your sleep quality.
- ▶ Manage your stress, practice relaxation, and identify sources of anxiety and stress.
- ▶ Adopt a balanced diet (follow the food guide).

SYSTEMIC SCLERODERMA AND CANCER

Sabrina Hoa, MD MSc FRCPC, Rheumatologist, Centre hospitalier de l'Université de Montréal

Valérie Hayes-Martel, MD, Rheumatology Resident, University of Montreal

Cancer affects about two in five Canadians over the course of their lives (1). Some individuals diagnosed with systemic scleroderma may also face a concomitant cancer diagnosis. This article discusses the association between scleroderma and cancer, as well as issues and precautions related to the treatment of scleroderma and cancer.

IS THERE AN ASSOCIATION BETWEEN SCLERODERMA AND CANCER?

Individuals with systemic scleroderma have a higher risk of cancer than the general population, particularly within the three to five years surrounding the scleroderma diagnosis. Research studies suggest that scleroderma may be a cross-reactive immune response that arises in the context of an anti-cancer response in certain individuals (2). In other words, the immune system detects cancer cells, tries to fight them by producing antibodies, but also develops antibodies that recognize the body's normal cells (autoantibodies), leading to the development of scleroderma. When scleroderma develops simultaneously with cancer, it is referred to as "paraneoplastic scleroderma."

SYSTEMIC SCLERODERMA AND CANCER

WHO IS AT RISK OF CANCER AROUND THE TIME OF A SCLERODERMA DIAGNOSIS?

The identified risk factors for paraneoplastic scleroderma are the presence of anti-RNA polymerase III and anti-U11/U12-RNP autoantibodies in the blood, as well as older age at the time of diagnosis. Anti-topoisomerase I (or anti-Scl70) autoantibodies may also be associated with a higher risk of paraneoplastic scleroderma, especially in older individuals. Traditional risk factors for cancer development, such as smoking, a strong family history of cancer, or significant unexplained weight loss, are additional elements that should raise suspicion of cancer (2).

IS THERE ALSO A RISK OF CANCER LATER IN THE COURSE OF SCLERODERMA?

Certain manifestations of scleroderma and some medications used to treat scleroderma may also increase the risk of cancer later in the disease. For example, lung fibrosis can increase the risk of developing lung cancer after several years. Chronic irritation of the esophagus due to uncontrolled reflux may also increase the risk of esophageal cancer. Individuals with a concomitant autoimmune liver or thyroid disease may also be at higher risk for cancer affecting these organs. Finally, cyclophosphamide, an immunosuppressive drug used in severe forms of scleroderma, may increase the risk of bladder cancer and hematological cancers, particularly in smokers (2).

WHAT TYPES OF CANCER ARE MOST ASSOCIATED WITH SCLERODERMA?

Individuals with scleroderma have a higher risk of lung, liver, esophageal, and blood cancers (multiple myeloma, leukemia, and lymphoma). Breast cancer is also associated with scleroderma, particularly in the year preceding or following the onset of scleroderma (2, 3).

SYSTEMIC SCLERODERMA AND CANCER

SHOULD I UNDERGO TESTS FOR CANCER SCREENING?

All individuals with scleroderma should undergo cancer screening tests recommended for the general population based on age, sex, and other risk factors (see Table 1) (4), along with a thorough physical examination by their doctor. It is important to note that screening programs vary by province and evolve over time based on available scientific evidence.

For individuals with a recent diagnosis of scleroderma and the risk factors for paraneoplastic scleroderma mentioned above, additional investigations may be considered. Some experts suggest, for instance, annual mammograms, an abdominal-pelvic ultrasound or CT scan, or even a positron emission tomography (PET) scan. However, the optimal screening approach remains to be determined, as few studies currently guide screening practice in patients at higher risk for paraneoplastic scleroderma (2).

Finally, for individuals who have been treated with cyclophosphamide as an immunosuppressive therapy for severe manifestations of scleroderma, annual tests for blood and cancer cells in the urine are recommended to screen for bladder cancer (2).

TABLE 1

TYPE OF CANCER	TARGET POPULATION	RECOMMENDED SCREENING
Breast Cancer	Women aged 50 to 74 years	Mammogram every 2 to 3 years
Cervical Cancer	Women aged 21 to 69 years who are or have been sexually active	Pap test every 3 years; screening may cease at age 70 if 3 consecutive tests have been negative in the past 10 years
Colorectal Cancer	Adults aged 50 to 74 years	Fecal occult blood test every 2 years or sigmoidoscopy every 10 years
	Family history of colorectal cancer in a first-degree relative	Colonoscopy every 5 to 10 years, starting at age 40 to 50 or 10 years before the relative's age at diagnosis
Lung Cancer	Adults aged 55 to 74 with a significant smoking history, who are currently smoking or quit within the last 15 years	Low-dose CT scan

CAN RADIATION THERAPY BE USED IN THE CONTEXT OF SCLERODERMA?

One of the possible side effects of radiation therapy is an exaggerated fibrotic reaction at the site of radiation, including the skin (leading to localized scleroderma or morphea) or the lungs (leading to localized pulmonary fibrosis). For this reason, there is concern that radiation therapy could also worsen skin and lung fibrosis in individuals with systemic scleroderma. Systemic scleroderma is therefore generally considered a relative contraindication to radiation therapy. In fact, a few cases have been reported in the literature of the onset or worsening of skin or lung fibrosis in individuals with scleroderma who received radiation therapy, particularly in the context of breast cancer.

However, in a large recent study reporting the experience of nearly 70 women with systemic scleroderma who received radiation therapy for breast cancer, exaggerated local skin fibrosis in the irradiated breast area was observed in half of the patients, and localized lung fibrosis at the irradiation site was observed in only 10% of patients (5). Moreover, no worsening of systemic scleroderma skin or lung involvement was observed.

Thus, radiation therapy is a therapeutic option that may be considered in individuals with systemic scleroderma but should be discussed, weighing the expected benefits on cancer against the potential associated risks.

IS CHEMOTHERAPY SAFE IN THE CONTEXT OF SCLERODERMA?

Chemotherapy is often the basis of cancer treatments, and the vast majority of these treatments are safe in the context of scleroderma. However, certain chemotherapies, notably taxanes (docetaxel, paclitaxel) and gemcitabine, are known to have the rare (<1%) side effect of inducing skin hardening similar to limited or diffuse scleroderma, and sometimes even severe Raynaud's phenomenon. Bleomycin can also induce pulmonary fibrosis and, more rarely, skin fibrosis (6, 7).

However, the safety of these drugs has not been specifically studied in individuals with systemic scleroderma. Nevertheless, given the rare but well-documented risks of drug-induced scleroderma, it is important that oncologists and rheumatologists discuss the risks, benefits, and treatment alternatives with the patient when such chemotherapy is being considered.

CAN IMMUNE CHECKPOINT INHIBITORS BE USED IN THE CONTEXT OF SCLERODERMA?

Immune checkpoint inhibitors (such as nivolumab, pembrolizumab, and durvalumab) are drugs that help the patient's own immune system to fight their cancer. These drugs have revolutionized the treatment of certain otherwise incurable cancers. However, in some patients, these drugs can overstimulate the immune system, leading to the onset of new autoimmune diseases, including scleroderma (<1%).

The safety of these drugs in individuals with systemic scleroderma was studied in 17 patients: 4 (24%) of them experienced a severe flare of their disease. The risk may be higher in patients with diffuse scleroderma (flare in 3/9) than in those with limited scleroderma (flare in 1/9), and particularly in those with the anti-RNA polymerase III autoantibody (flare in 2/2) (8).

Ultimately, the risks and benefits of treatment with an immune checkpoint inhibitor must be discussed with the patient in close collaboration with their oncologist and rheumatologist.

CONCLUSION

In summary, individuals living with scleroderma are at a higher risk of developing cancer compared to the general population. Cancer screening is recommended and should be personalized based on age, sex, and risk factors. Radiation therapy, chemotherapy, and immune checkpoint inhibitors are therapeutic options that can be considered. Close collaboration between the rheumatologist, oncologist, and patient is necessary to discuss the risks, benefits, and treatment alternatives, in order to minimize the risks of exacerbating the autoimmune disease while maximizing the chances of curing the cancer.

REFERENCES :

1. Canadian Cancer Statistics Advisory Committee, in collaboration with the Canadian Cancer Society, Statistics Canada, and the Public Health Agency of Canada. Toronto (Ontario) Canadian Cancer Society; 2023 [Available from: cancer.ca/Canadian-Cancer-Statistics-2023-FR].
2. Weeding E, Casciola-Rosen L, Shah AA. Cancer and Scleroderma. Rheum Dis Clin North Am. 2020;46(3):551-64.
3. Bonifazi M, Tramacere I, Pomponio G, Gabrielli B, Avvedimento EV, La Vecchia C, et al. Systemic sclerosis (scleroderma) and cancer risk: systematic review and meta-analysis of observational studies. Rheumatology (Oxford). 2013;52(1):143-54.
4. Chaput G, Del Giudice ME, Kucharski E. Cancer screening in Canada: What's in, what's out, what's coming. Can Fam Physician. 2021;67(1):27-9.
5. Shah DJ, Hirpara R, Poelman CL, Woods A, Hummers LK, Wigley FM, et al. Impact of Radiation Therapy on Scleroderma and Cancer Outcomes in Scleroderma Patients With Breast Cancer. Arthritis Care Res (Hoboken). 2018;70(10):1517-24.
6. Ketpueak T, Chanloung W, Nan KN, Pongsananurak C, Kasitanon N, Louthrenoo W. Paclitaxel-induced diffuse scleroderma with possible scleroderma-renal crisis: a case report and literature review of taxanes-induced scleroderma. Clin Rheumatol. 2022;41(12):3887-96.
7. Cappelli LC, Shah AA. The relationships between cancer and autoimmune rheumatic diseases. Best Pract Res Clin Rheumatol. 2020;34(1):101472.
8. Panhaleux M, Espitia O, Terrier B, Manson G, Maria A, Humbert S, et al. Anti-programmed death ligand 1 immunotherapies in cancer patients with pre-existing systemic sclerosis: A postmarketed phase IV safety assessment study. Eur J Cancer. 2022;160:134-9.

Community Contact Representatives

CONNECT WITH THE SCLERODERMA COMMUNITY IN YOUR AREA!

Give us a call, send us an email, and meet other people living with scleroderma.

604-984-9425
sabc.rq@telus.net

Campbell River

Jackie Alexander
250-830-7287
jackie.alex97@gmail.com

Chilliwack

Kelly Grant
604-378-1806
thekellygrant@gmail.com

Creston

Betty Kuny
250-428-8875
rkuny@telus.net

Kamloops

Jen Beckett
250-574-3151
jenniferbecketts@hotmail.com

Kelowna

Angie Reglin
250-860-5700
angiereglin@gmail.com

Nanaimo

Linda Allen
llallen.52.14@gmail.com

Nelson

Sylvia Reimer
250-551-0973
reim1syl@gmail.com

Valemount & Northern Rural Communities

Teressa Colosimo
250-566-3165
pattess72@hotmail.ca

Vancouver

Suzanne Gavin
604-710-8722
suzannergavin@gmail.com

Victoria

Susan Goss
250-479-8586
susangoss@shaw.ca

Williams Lake

Cecelia Jaeger
250-392-3656
cecejaeger@gmail.com

Yellowknife

Helen White
867-873-5785
hwhite@theedge.ca

A Huge Thank You to Janssen PHARMACEUTICAL COMPANIES OF Johnson&Johnson

The realization and mailing costs of a magazine are important elements of the budget of a charitable organization such as ours.

For this reason, we want to emphasize the generous gesture of our partner, Janssen Canada which, thanks to an educational grant, made production, printing and distribution of this Fall-Winter Bulletin possible.